



“Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship”

Meeting: Tuesday December 17, 2019 3:30pm – 5:30pm
451 Junction Road
Madison, WI
UW West Clinic Room 1287

Enter the clinic... turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

Group Information:

Jayne Schwartz 608- 244-2120
schwartzdon@sbcglobal.net

Madison Multiple Myeloma Support Group website
madisonmultiplemyeloma.org

Mailing Address: Wisconsin Multiple Myeloma Support Group
3309 Chicago Avenue Madison, WI 53714-1815

Information Sources :

International Myeloma Foundation (IMF)
Phone: 800 - 452 - 2873
Email: TheIMF@myeloma.org
Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
Phone: 203 - 972 - 1250
Email: info@themmrf.org
Website: www.multiplemyeloma.org

Upcoming Meeting Speakers... Mark your calendars now!

Cameron Ninos from the UW Cancer Pharmacy will be our January meeting speaker. He will not be speaking to the “cost” of medications but will do a Q & A for other questions. I am asking for questions in advance so that I can forward a list. This will help him prepare to get the conversation started. He will be here at 4:30pm.

Dr Aric Hall will be our featured speaker for the March meeting. He will do a Q & A session starting at 4:30pm.

Dr Shannon O'Mahar will be our featured speaker for this December meeting. She may be presenting 2019 ASH conference highlights. Mark your calendar now!

Looking to make that last minute contribution before the year is over? How about making a donation to the Trillium Fund? See information below on how to do it. Remember, all money stays here at the UW Carbone Cancer Center for research.

Early results of the Iceland Study- iStopMM

The acronym iStopMM stands for Iceland Screens, Treats, or Prevents Multiple Myeloma. The

project's main goal is to assess the impact and outcomes from early screening for MGUS, SMM (smoldering myeloma), and active myeloma for all of Iceland. The participation rate was approximately 80,000 adults over age 40 producing the largest screening project for any type of cancer ever conducted. As part of the iStopMM study protocol, one-third of the patients with MGUS went through a very detailed baseline testing, including bone marrow evaluation and whole-body CT scanning.

Currently, the standard procedure is to simply monitor patients with very low-level MGUS. However, in this study the bone-marrow testing revealed that 16% of the MGUS patients actually had SMM (smoldering multiple myeloma)—a higher level of disease, which requires closer monitoring. This finding will most likely be practice-changing, meaning that bone-marrow testing does need to be performed for MGUS patients at baseline.

In addition, 16 patients have been discovered to have previously unknown active myeloma needing treatment. New classification systems for MGUS and SMM will undoubtedly emerge. It will be known which patients to monitor and how, as well as which patients to treat early.

Co Pay assistance programs update....

As of **December 4, 2019:**

Healthwell has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit **Healthwell page**.

The **Leukemia & Lymphoma Society (LLS)** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit **LLS page**.

The **Patient Advocate Foundation (PAF)** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit **PAF page**.

Patient Access Network Foundation (PANF) has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit **Patient Access Network Foundation page**.

If you are in need of co-pay assistance, you are also encouraged to contact the patient support programs of the drug manufacturers directly:

Celgene

- Thalomid, Revlimid, & Pomalyst
- Celgene patient support web portal

Takeda

- Ninlaro 1Point Program
- Velcade Support

Amgen

- Kyprolis
- Amgen Assist 360 Program

Janssen

- Darzalex

- Janssen CarePath Program

A Message from Froedtert and the Medical College of Wisconsin Cancer Center:

Just a quick note to let you know that the presentations from this year's Multiple Myeloma symposium have been posted and are available for viewing/download. Many of the files are too large to email so please visit this link to access: <https://www.mcw.edu/departments/cancer-center/patient-resources/Annual-Multiple-Myeloma-Patient-and-Caregiver-Symposium>

Mark you 2020 calendar for the next conference. **Save the date: 9/19/20!**

Don't forget to send me your questions for our upcoming meeting with the UW pharmacist.

IMF Info Line – If you or someone you care for has Myeloma, you have questions. Probably, lots of them. You can search the Internet all you want, but other than asking your doctor, there is no better way to get your questions answered than to call the IMF Info Line. Missy, Judy and Paul know their stuff and they want to share what they know with you. Just ask anyone who has called the IMF Info Line. Patients or caregivers are welcome to contact the Info Line staffed by trained specialists at 800-452-CURE (800-452-2873). The Info Line is staffed between 9am and 4pm Pacific Time, 11am to 6pm Central time or infoline@myeloma.org.

New information!

The Trillium Fund was established by our founding support group members to facilitate Multiple Myeloma research here in Madison at the Wisconsin Institute of Medical Research. If you or your family wish to donate or send a memorial to this program, checks can be made payable to the “UW Foundation – Trillium Fund” and sent to UW Carbone Cancer Center, University of Wisconsin Foundation, 1848 University Ave, Madison, WI 53726. Donations may also be made online at www.supportuw.org/give (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Daniel Rosen at (608) 264-5437 or email curecancer@supportuw.org.